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ABSTRACT

Insulin dependent diabetes is an incurable disease requiring complex management by the patient and/or his family. Previous research has found that there is no specific personality type associated with this or other diseases, nor do chronically ill persons exhibit characteristic behavioral or emotional problems. An attempt to identify the cognitive, affective, and behavioral parts of adjustment to childhood diabetes involved two instruments for measuring diabetes attitudes. The Diabetes Opinion Survey measures the child's attitudes on stigma, rule orientation, divine intervention, family interruption, and sick role. The Parent Diabetes Opinion Survey measures stigma, rule orientation, divine intervention, family interruption, manipulativeness, attitudes toward medical staff, reactions: observations/detection, and consumption of sweets. Compliance was found to be reliably measured using 24-hour recall interviews with mother and child questioning five areas: (1) insulin injection; (2) diet: type; (3) diet: amount; (4) exercise; and (5) eating/testing frequency. The results suggest that measures of chronically ill children's adjustment must be disease specific. (ABL)

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ADJUSTING TO CHILDHOOD DIABETES

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Abstract

Early psychological research in the area of childhood diabetes focused on the presumed personality/adjustment problems of this population. Today, it is generally accepted that children with this disorder cope remarkably well. Nevertheless, the disease places numerous demands upon the patient and the family. These demands occur in the cognitive, behavioral, and affective spheres. Diabetes-related learning and behaviors must be acquired. At the same time the patient develops attitudes about the disease as it relates to interactions both within and outside of the family.

Over the last several years we have studied patient and parent responses to childhood diabetes using measures of diabetes knowledge, management behaviors, and attitudes toward the disease. We have not attempted to intervene, but rather, have chosen the more naturalistic approach of studying children and families' "usual" response to such a disorder. Today I would like to share with you the highlights of what we have learned.

Mothers typically know more about diabetes than any other family member. Patients' knowledge seems to be closely tied to cognitive development. Although patients are often encouraged to take a great deal of responsibility for their disease, our research suggests that many tasks cannot be accurately accomplished until the youngster is at least 12 years old. Instead of treating all children the same, we are beginning to delineate what aspects of the disease and its management should be taught at what ages.

Our studies on diabetes management behaviors suggest that adherence or compliance is not a unitary concept: adherence with one aspect of the diabetes regimen does not predict adherence with other aspects of the treatment program. Parents know less about adolescents' management behaviors than the same behaviors

of pre-adolescents. Adolescents also show poorer adherence behavior, suggesting that parents may give patients too much responsibility too early.

Factor analytic studies conducted at our institution indicate that parents and patients hold some beliefs about the disease in common (e.g. how much diabetes is a stigma and how disruptive it is to the family). In other respects parents and patients differ in their diabetes-related attitudes (e.g. patients are concerned with sick role behavior while parents focus on their supervisory role and the child's use of the disease in a manipulative fashion). The importance of these attitudes to the child's and family's management of the disease and to their functioning in non-diabetes relevant areas remain to be seen.

ADJUSTING TO CHILDHOOD DIABETES

Insulin dependent diabetes, the most common endocrine disorder of childhood, is characterized by insufficient insulin production by the pancreas. (SLIDE) Daily insulin replacement by injection is necessary for survival. In addition, the patient must eat frequently (3 meals and 3 snacks are recommended), avoid concentrated sweets, exercise regularly, and monitor blood glucose either by urine test or by obtaining a small sample of blood from a finger stick. Such tests are recommended on a twice daily basis. There is no cure for diabetes. Management of the disorder is complex. While insulin replacement by injection is necessary and helpful, it is insensitive to blood glucose fluctuations that result from eating, exercise, stress, and illness. Consequently, the patient must continually monitor blood glucose levels and adjust some component of the treatment regimen in order to maintain blood glucose levels as close to normal as possible. Nevertheless, some excursions in blood glucose are to be expected. The patient must be able to recognize signs of abnormally low (hypoglycemia) or abnormally high (hyperglycemia) blood glucose. Hypoglycemia or insulin shock requires immediate action, or coma and even death may ensue. Clearly, adjusting to a life with diabetes is a remarkable undertaking.

(SLIDE) Initial research on adjustment to diabetes was influenced by early psychosomatic models. Different personalities were presumed to be associated with different illnesses. This approach is no longer taken seriously; we have given up looking for the "diabetic", the "cardiac", or the "asthmatic" personality. This does not mean that personality variables are necessarily unimportant. Rather, specific personality types do not seem to be associated with specific diseases.

A second characteristic of past research, is that investigators frequently compared "ill" groups to healthy or so-called "normal" controls. This approach was based upon the underlying assumptom that chronically ill populations would evidence more psychopathology than healthy populations. The psychopathology was presumed to be the result of the illness itself or, as in the personality research mentioned previously, the individual's personality or psychopathology was somehow causally linked to the development of a particular illess. We now know that most persons with a chronic illness cope remarkably well and while certain individuals may exhibit behavioral or emotional problems, this is not necessarily a characteristic of the population as a whole.

A third characteristic of past research is its univariate nature. By this I mean that most investigators chose to study only one variable and that variable was usually within the patient, i.e., the patient's personality or general level of adjustment.

Our current work on adjusting to childhood diabetes departs markedly from these past research efforts. (SLIDE) First, instead of focusing on the patient's personality, we have attempted to elucidate what are the cognitive, affective, and behavioral components to the adjustment process. Second, we are interested in how adjustment and health status interrelate (i.e. is the patient's health or diabetic control related to the patient's knowledge about the disease, attitude toward it, and daily diabetes management behaviors?) Third, we have emphasized model specificity in that we are interested in cognitions, feelings or attitudes, and behaviors directly related to diabetes. As a consequence, we have developed disease specific measures of each of these constructs. Finally, we are interested in multivariate models. By multivariate we mean both multiple patient characteristics (in the cognitive, affective and behavioral spheres) and multiple person variables (the patient and the parent).

We assume that no single variable adequately explains adjustment/health status relationships. We assume that such relationships are sufficiently complex that they must be studied from a multivariate perspective. (SLIDE) We have developed a simple beginning model. In this model, knowledge of diabetes represents the cognitive components of adjustment, attitudes toward the disease represents the affective component, and adherence or compliance represents the behavioral component. We are interested in how these variables relate to health status or diabetic control. Our constructs are highly specific; measures were developed for childhood diabetes (as opposed to chronic illness in general). And, our model includes both multiple patient variables and multiple persons (parent and child).

What appears to be a relatively simple model is actually quite complex. Let us take knowledge about the disease. (SLIDE) Upon reflection, we identified at least three components of diabetes knowledge: General Information (i.e., facts about diabetes); Problem Solving (i.e. how you use what you know about the disease in different situations); and Skill (i.e. insulin injection, urine testing, blood glucose assessment). We developed reliable measures of each type of diabetes knowledge. (SLIDE) When we interrcorrelated patients' performance on these measures we found that General Information and Problem Solving were moderately related but the different skills tests were not strongly related to General Information, Problem Solving, or to each other. These findings have two important implications. First, there is no quick assessment of patient or parent knowledge; you must assess each aspect of disease knowledge you consider important. Second, knowledge of diabetes is a complex construct, consisting of several specific and relatively independent components.

Measuring patient and parent attitudes toward the disease resulted in somewhat similar conclusions. After several years of work in which we developed diabetes specific attitude questionnaires, we were able to identify five patient

attitudes and eight parent attitudes that we could measure reliably and could verify by factor analysis. (SLIDE) The Diabetes Opinion Survey (DOS) measures the child's attitudes which consist of: Stigma, Rule Orientation, Divine Intervention, Family Interruption and Sick Role. (SLIDE) The Parents Diabetes Opinion Survey (PDOS) measures: Stigma, Rule Orientation, Divine Intervention, Family Interruption, Manipulativeness, Attitudes Toward Medical Staff, Reactions: Observations/Detection; and Sweet Consumption. While some attitudes toward diabetes were similar for parent and child, there were substantial differences as well. Further, attitudes toward the disease are complex, consisting of several relatively independent components.

Measuring diabetes management behaviors represented, perhaps, our greatest challenge. We finally settled on using 24-hour recall interviews with mother and child separately on three different occasions. Using these data we measure 13 different adherence behaviors and have demonstrated relatively good parent/child agreement for each. We subjected these data to a principle component factor analysis. A five factor solution resulted which was rotated to simple structure. (SLIDE) The results suggested that daily diabetes management consists of five independent components: Insulin Injection; Diet: Type; Diet: Amount; Exercise; and Eating/Testing Frequency. Compliance or adherence, then, is <u>not</u> a simple or unitary concept. Physicians typically described patients as "compliant" or "non-compliant" suggesting that this is a general characteristic of the patient. Our findings suggest that such use of the term is inaccurate and potentially very misleading. A patient can be compliant or adherent with one aspect of diabetes management and non-adherent with another. In fact, knowing the patient's adherence with one aspect of diabetes management <u>tells us nothing</u> about the same patient's behavior in any other area of the diabetes treatment regimen. Once again, there is no simple way to assess patient compliance or adherence; all aspects of the management regimen must be assessed.

What can we conclude from our efforts to date? There is little doubt that patient adjustment to chronic illness is an important area of study. We remain committed to better delineating adjustment/health status relationships. Nevertheless this cannot be done quickly or easily. Our work suggests that general measures of adjustment to chronic illness should be avoided. Each disease places its own demands upon the patient and family. As we have shown, the cognitive, affective, and behavioral components of adjusting to diabetes are specific and complex. It seems likely that similar comlexity will exist with any other chronic illness. This suggests that specific measures of adjustment must be developed for each disease. This is probably not a popular conclusion since a time-consuming commitment to measurement development is its unescapable consequence. This is not a problem exclusive to psychololgy or the measurement of adjustment. There are few general measures of health status; measures of chronically ill patients' physical well-being are disease specific. It should come as no surprise, then, that measures of chronically ill patients' psychological adjustment to their disease must be disease specific as well. While this approach may not be popular, we feel that it is necessary. Perhaps most importantly, our efforts to date suggest that reliable disease specific measures can be developed, demonstrating that such an approach is realistic and viable.